313 Health-related quality of life in Russia: Data on the CFQ-R in children with cystic fibrosis

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Objectives: Cystic Fibrosis (CF) is a chronic, progressive and life-shortening disease. Life expectancy has increased substantially in recent decades due to early diagnosis and improved treatment. Health-related quality of life (HRQOL) measures are patient-centered and provide information about the patient's own assessment of his respiratory symptoms, physical, social, and emotional functioning and well-being.
Methods: 40 children with CF completed the age-appropriate Russian version of the CFQ-R. Forced expiratory volume in 1 second (FEV_1% predicted), body mass index (BMI) and intravenous antibiotic treatment (IV) were utilized as measures of health status.
Conclusion: On average, scaled scores on the CFQ-R were as follows: Physical Functioning (70.9±25.5), Emotional Functioning (72.2±15.6), Eating Disturbances (69.7±25.7), Treatment Burden (74.4±18), Social Functioning (63.7±17.7), Body Image (82.7±21.6), Respiratory Symptoms (67.7±25.7) and Digestive Symptoms (72.5±24.9). Intraclass correlation coefficients measuring parent–child agreement ranged from r = 0.47 to 0.74 (p's <0.001), indicating very good agreement. Significant associations were also found between lung function and CFQ-R Physical Functioning (r = 0.36, p = 0.02) and Respiratory Symptoms (r = 0.55, p = 0.000). No associations were found between BMI and CFQ-R scales. A trend was also found between number of IV courses and CFQ-R Physical Functioning (r = –0.43, but p = 0.07).
This pilot study of the Russian version of the CFQ-R demonstrated strong convergent validity. This Russian translation of the CFQ-R can be used to evaluate HRQOL in children with CF, including use in drug trials and observational studies.

314 Mapping the Cystic Fibrosis Questionnaire-Revised (CFQ-R) to a preference based utility index

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Objectives: Economic evaluations of new treatments are measured in terms of quality-adjusted life years (QALYs). QALYs require utility data (e.g. EQ-5D data) which is often not collected in clinical trials. The Cystic Fibrosis Questionnaire-Revised (CFQ-R) is a well validated and utilised CF patient reported outcome measure. This study aimed to develop a mapping algorithm to estimate EQ-5D utility values from the CFQ-R.
Methods: Adults with Cystic Fibrosis (CF) were recruited by the CF Trust in the UK to complete an online survey including the CFQ-R, EQ-5D and a clinical/demographic form. Statistical mapping between the CFQ-R and EQ-5D was estimated using three different methods: ordinary least square (OLS) regression, Tobit, and Two-Part Models (TPM). Items, domains, squared terms and covariates were considered. All models were assessed using goodness of fit and model predictive performance statistics.
Conclusion: 401 CF patients participated (61% females), age 18–26 yrs, with a broad range of lung function compromise (mild – severe). All 3 regression methods performed well using both domain level and item level models: OLS (root mean square error [RMSE] = 0.174 and 0.171), TPM (RMSE = 0.127 and 0.096), and Tobit (RMSE = 0.173 and 0.136). The best performing model was the item level TPM, including age and gender covariates with a difference of 0.008 between observed (0.671) and predicted (0.679) EQ-5D scores.
This study provides mapping algorithms strongly correlating CFQ-R to the EQ-5D. These algorithms can be used to estimate utility values from CFQ-R scores for economic analysis in datasets without a preference based measure.

315 Quality of life assessment in cystic fibrosis − Use of the Rasch latent trait model

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Introduction: Disease specific tools exist for assessing the quality of life (QoL) of People with Cystic Fibrosis (PWCF) with no global measure that captures the overall balance from various QoL spheres. We present a single QoL score based on a latent trait model.
Methods: Responses from the Cystic Fibrosis Questionnaire (CFQ-R) collected in 2007 were analysed. These were grouped into the 12 domains and transformed into percentages with higher values indicating better QoL in the domain. The scores were then dichotomized at the median and a one parameter Rasch model fit to estimate a single value considered the overall measure of QoL. This measure depends on the individual performance in each domain considering its difficulty and on how other respondents performed and ranges between –6 and +6 with higher positive scores showing better overall QoL.
Results: Among the 248 PWCF (5.3–55.5 years), 51.0% were males with 63.0% aged 18 or over. The highest scores, mean±SD, were in the digestive symptoms (75.1±22.1) domain while the lowest were in social functioning (53.8±23.1). On the new scale, the easiest and most difficult items were in weight problems and social functioning with difficulty parameters –1.16 and +1.25 respectively. The overall QoL score had values between –1.65 and 2.47 with mean±SD of 0.4±1.0.
Conclusions: It is difficult to compare individuals or make an overall assessment of QoL using several percentages. The single score is easy to interpret and utilizes more information. It gives a single quantitative measure and simplifies longitudinal assessment even with some missing data.

316 Preliminary results of the Quality of Life Systemic Inventory for children in pediatric cystic fibrosis: A tool for clinical interventions?

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Objective: This study examined the generic and CF-specific QOL in CF children using a tool based on a modular clinical approach.
Method: Sample consisted of 12 CF children and 12 healthy children aged 8 to 12 years, matched by age and sex. The Quality of Life Systemic Inventory for Children (QLSI-C) assess both generic (20 items) and CF-specific (6 items) QOL. CF-specific module is empirically created from CFQ-R and discussion with medical staff. QLSI-C is a dynamic tool, using a VAS, which considers QOL (gap) like the difference between the present situation (state) and the expectations (goal). This difference is weighted by the importance (rank) that children assign for each life domains. QLSI-C is different from PedQoL, which consider QOL like an assessment of state score only.
Results: Difference between CF and healthy children for the QOL score approached significance (F = 3.63; p = 0.07). Results by items show a significant difference for "autonomy" (F = 4.30; p = 0.05) and "frustration tolerance" (F = 4.60; p = 0.04) between the two groups. In addition, global scores in CF-specific module is correlated with global score in generic module for CF children (r = 0.66 to 0.96). Assessment of QOL is the same for both generic (M = 3.76) and CF-specific (M = 3.76) module (p = 0.53). Finally, descriptive statistics demonstrate that items which reflect the best QOL in CF children were based on social support unlike healthy children.
Conclusion: QLSI-C is a clinical tool which distinguishes between children with CF and healthy children. Originality of this tool is strengthened by the consideration of individual life plan taking into account the particular situation of children with CF.